

Message Text

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FM AMEMBASSY MOSCOW

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C O N F I D E N T I A L MOSCOW 13506

E.O. 11652: GDS

TAGS: TGEN, TBIO, PFOR, US, US

SOBJ: SOVIET TREATMENT OF RETINITIS PIGMENTOSA

BEGIN UNCLASSIFIED

1. EMBASSY HAS LEARNED INFORMALLY THAT SCI COUNS-DESIGNATE GREEBERG WILL START HIS PRE-DEPARTURE BRIEFINGS ABOUT 1 SEPT. EMBASSY SUGGESTS THAT BRIEFINGS BE ARRANGED FOR GREENBERG BY DHEW AND OR NIH (E.G., FOGARTY INTERNATIONAL CENTER) ON U.S. ASSESSMENT OF SOVIET TREATMENT METHODOLOGY FOR RETINITIS PIGMENTOSA, AS RECENT DEVELOPMENTS PRESENT TICKLISH SITUATION RE SOVIET TREATMENT OF FOREIGNERS.

2. BEGIN BACKGROUND. RETINITIS PIGMENTOSA IS A DEGENERATIVE DISEASE OF THE EYES WHICH IS ASSOCIATED WITH LOSS OF NUCLEIC ACIDS FROM THE RETINA. VICTIMS GRADUALLY LOSE THEIR EYESIGHT.

3. SOVIETS (HELMHOLTZ INSTITUTE) HAVE DEVELOPED FOR THE DISEASE A TREATMENT USING NUCLEIC-ACID INJECTIONS, AND THEY CLAIM (NO STATISTICS PROVIDED) THAT 47 PERCENT OF THE PEOPLE TREATED HAVE SHOWN SLOWING OR ARRESTATION OF THE DISEASE'S PROGRESS DURING TREATMENT.

4. BRITISH PUBLIC HEARD OF THIS TREATMENT, AND ABOUT 60 BRITISH HAVE INQUIRED ABOUT IT. FIFTEEN HAVE RECEIVED TREATMENT HERE.

5. THIS EMBASSY HAS ALSO RECEIVED SEVERAL INQUIREIES FROM U.S. CITIZENS, TWO OF WHICH WERE SENT WITH CONGRESSIONAL INTEREST
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(LIVINGSTONS OF MASSACHUSETTS--KENNEDY--SEE MOSCOW 0927; CASALE

OF PENNSYLVAIN--SCHWEIKER--SEE MOSCOW 10777). IN EACH CASE, WE HAVE FORWARDED THE REQUEST TO THE SOVIET MINISTRY OF HEALTH. AND HAVE SUGGESTED TO THE U.S. CITIZENS THAT THEY MAY WISH TO CHECK WITH DHEW (COPIES WERE SENT ROBERT FISCHER, DHEW/OIH). END BACKGROUND. END UNCLASSIFIED.

6. BEGIN CONFIDENTIAL. BRITISH SCI COUNS HAS ADVISED THAT BRITISH SPECIALIST VISITED HELMHOLTZ INSTITUTE IN FEBRUARY, AND THAT SUBSEQUENT BRITISH DOUBTS OVER EFFICACY OF SOVIET TECHNIQUE LED BRITISH TO SEEK AGREEMENT FROM SOVIETS TO ALLOW HMG ESSENTIALLY TO TELL BRITISH CITIZENS INQUIRING INTO POSSIBILITIES OF TREATMENT THAT: (1) PROGRAM LIMITED AND EXPERIMENTAL, AND (2) THAT NO BRITONS COULD BE ACCEPTED UNTIL STATUS OF TREATMENT CHANGED. ACCORDING TO BRITISH SCI COUNS, SOVIETS WERE ON POINT OF SUCH AGREEMENT WHEN OTHER BRITISH PHYSICIANS, WHO APPARENTLY HAD ACCESS TO SPECIALIST'S REPORT, INFORMED BRITISH PRESS THAT SOVIET TREATMENT WAS "WORTHLESS" AND "A HOAX", ACCORDING TO BRITISH SCI COUNS, SOVIETS HAVE SINCE INFORMED BRITISH EMBASSY THAT "SOVIET LAW REQUIRES" THAT PATIENTS NEEDING TREATMENT RECEIVE IT, AND THAT SOVIETS WILL THEREFORE ACCEPT BRITONS WHO REQUEST AND NEED TREATMENT. END BACKGROUND.

7.COMMENT: THE BRITISH ATTEMPT AT A FINESSE LANDED THEM ON BOTH THE ROCK AND THE HARD PLACE, A PERFORMANCE WE WOULD LIKE TO AVOID. YET WE MUST AVOID A FLOOD OF U.S. CITIZENS APPLYING FOR TREATMENT WHICH IS AT BEST UNPROVEN AND AT WORST HARMFUL. OUR OPTIONS SEEM LIMITED, PARTICULARLY SINCE A NUMBER OF AMERICANS HAVE ALREADY REQUESTED TREATMENT (THE THREE LIVINGSTON CHILDREN HAVE ALREADY RECEIVED THEIR INITIAL TREATMENT). IF DHEW HAS INSUFFICIENT INFORMATION ON SOVIET TREATMENT, PERHAPS "TAKING THE OFFENSIVE" IS THE BEST COURSE, FOR EXAMPLE HAVING DHEW REQUEST FROM THE SOVIETS EITHER CLINICAL RESULTS OR SAMPLES SO THAT TESTS MIGHT BE RUN IN THE U.S. (BRITISH SCI COUNS SAID THAT THAT WOULD BE THE APPROACH FOR THE BRITISH, BUT THAT THE CURRENT ADVERSE PUBLICITY HAS DOOMED THE POSSIBILITY OF ANY BRITISH SPECIALIST PERFORMING THE TESTS). BRITISH SCI COUNS IS PERSONALLY UNCONVINCED, FROM A SCIENTIFIC VIEWPOINT, OF EFFECTIVENESS OF SOVIET TECHNIQUE. BUT HE ALSO STRESSED THAT VISITING BRITISH SPECIALIST ARRIVED "ALREADY CONVINCED, WITH A CLOSED MIND", THAT THE SOVIET

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TECHNIQUE WAS WORTHLESS.

8. DHEW'S REQUESTING CLINICAL DATA OR SAMPLES WOULD ALLOW USG TO TAKE A POSTURE THAT TECHNIQUE IS BEING INVESTIGATED, AND THAT RECOMMENDATIONS WOULD HAVE TO AWAIT RESULTS. THIS STEP COULD AVOID SOME KIND OF REPEAT OF THE BRITISH DILEMMA. END COMMENT.

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